



National Anti-Stigma Campaign (NASC): Building Partnerships that Work

February 7, 2007



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Center for Mental Health Services
www.samhsa.gov

www.stopstigma.samhsa.gov



Survey

We value your suggestions. Within 24 hours of this teleconference, you will receive an e-mail request to participate in a short, anonymous online survey about today's training material. Survey results will be used to determine what resources and topic areas need to be addressed by future training events. The survey will take approximately five minutes to complete.

Survey participation requests will be sent to all registered event participants who provided e-mail addresses at the time of their registration. Each request message will contain a Web link to our survey tool. Please call **1-800-540-0320** if you have any difficulties filling out the survey online. Thank you for your feedback and cooperation.

Written comments may be sent to the Substance Abuse and Mental Health Services Administration (SAMHSA) ADS Center via e-mail at stopstigma@samhsa.hhs.gov



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Contact Us

SAMHSA ADS Center

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*The Moderator for this call is **Michelle Hicks**.*



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Questions?

At the end of the speaker presentations, you will be able to ask questions. You may submit your question by pressing **'01'** on your telephone keypad. You will enter a queue and be allowed to ask your question in the order in which it was received. On hearing the conference operator announce your name, you may proceed with your question.



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Speakers

Chris Marshall, Consumer Affairs Specialist

As a consumer affairs specialist and project officer for CMHS, Chris leads many activities and programs that promote the meaningful participation of consumers in the mental health system and in mental health policy development. Chris focuses on issues of recovery, self-care, peer support, consumer education, privacy of health care information, discrimination and stigma, aging, and others. Chris is the project officer for SAMHSA's National Anti-Stigma Campaign, a nationwide public education effort that develop and distribute television, radio, and print public service announcements. Chris leads dialogue and regional consumer meetings and is also the lead staff for the CMHS National Advisory Council's Subcommittee on Consumer/Survivor Issues. Chris also is a self-identified consumer who has spoken out on these issues in press conferences, TV interviews, and other media.



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Speakers

Anna Scheyett, M.S., M.Phil., M.S.W., L.C.S.W.

Anna Scheyett is a Clinical Associate Professor at the University of North Carolina at Chapel Hill School of Social Work, where she teaches health and mental health courses in the Masters program. Anna received her Master's in Social Work from the University of North Carolina at Chapel Hill, has Master's in Science and Philosophy from Yale University, and is "all but dissertation" from the School of Social Work at Memorial University in Newfoundland, Canada. She has consulted, researched, and trained in the areas of adult health and mental health services, with particular interest in case management, psychiatric advance directives, stigma, and HIV.



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Speakers

Carmen Lee, Director, Stamp Out Stigma

Carmen suffers from an anaclitic depression that has caused her to be hospitalized collectively for 20 plus years. Her illness surfaced in the early 60's when Carmen was 23; at this time, long hospitalizations were deemed a necessary part of treatment. As a child, Carmen knew something was wrong, but thought everyone felt the same way and assumed they were pretending to be joyous and happy. She struggled through life accomplishing a lot even though it took much more energy than for most people. She went to college, became an airline stewardess, then married and had one child. With the responsibilities of caring for a young daughter, and living in a strange city, Carmen began to slip away into a deep depression and eventually catatonia. Thus began her years of hospital settings, shock treatments, medications and psychotherapy. In 1967 a prefrontal lobotomy was recommended, but Carmen's then-husband would not sign the papers. It's the one-on-one talk therapy that really enabled Carmen to reach a functioning and comfortable level of living and productivity. It's been many years since Carmen has been in the hospital, and she has made numerous contributions to both the mental health and general community. In 1985, she began the local Network of Mental Health Clients, and then in 1990 developed Stamp Out Stigma, which is nationally recognized as an effective program to address stigma and discrimination. Carmen also served as a county commissioner for eight years, is currently a member of the California State Mental Health Council, as well as the consumer representative on the federally funded Western States Decision Support Group. Carmen believes that anyone, if they accept and work around their illness, can take something that has been painful and negative and turn it around for a positive force for change.



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Speakers

Sarah O'Brien, Director, In Our Own Voice

Sarah graduated in 2001 with a BA from Goucher College. She became a NAMI “In Our Own Voice” Presenter in 2001 and a National Trainer for the program in 2003. “In Our Own Voice” is a public speaking program for consumers created by the National Alliance on Mental Illness (NAMI). In 2004 and 2005 Sarah worked as the Peer Education and Support Group Coordinator for NAMI Montgomery County, MD. In 2006 she took the position of IOOV Program Director at NAMI’s national office. It is Sarah’s joy to dedicate her work to something she cares so deeply about—recovery for those with mental illness and the discovery of a voice with the power to break down stigma. Sarah lives with bipolar disorder.



National Mental Health Anti-Stigma Campaign

February 7, 2007

Chris Marshall
Consumer Affairs Specialist
Center for Mental Health Services
SAMHSA/HHS

What a Difference a Friend Makes

Target:

18- to 25-year-old friends of people living with a mental illness.

Key Message:

Be the first step in a friend's recovery by supporting them if they have a mental illness.

Call to Action:

- **Be there for your friend if they have a mental illness.**
- **Visit whatadifference.org for more information.**



Campaign Elements

TV

- **Three executions in various lengths.**
- **Spanish version being created.**

Radio

- **Three executions in various lengths.**
- **Spanish version being created.**

Print

- **Creative executions in various sizes.**

Outdoor

- **30-sheet, 8-sheet, Bus Shelters**



Campaign Elements

Website

Brochure

Site Kit

SAMHSA/CDC Report

NASC Fact Sheet

Developing a Stigma Reduction Initiative –
available online via the ADS Center Web
site: *<http://stopstigma.samhsa.gov>*



How to Obtain Materials

- www.whatadifference.org
- SAMHSA National Mental Health Information Center
1-800-789-2647



Contact NASC Liaisons

ADS Center—Technical Assistance

The ADS Center provides additional reinforcement and support in order to equip state and community representatives to engage in anti-stigma efforts related to the NASC on the local level.



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Contact NASC Liaisons:

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Elizabeth Edgar

National Alliance on Mental Illness

NASC Liaison

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Consumer and Social Work Students in Dialogue

Anna Scheyett
Clinical Associate Professor
School of Social Work
University of North Carolina at Chapel Hill

Combating Stigma

- **Social Contact** (Couture & Penn, 2006; Penn, 1994, 1999)
 - Mediates education
 - Direct, personal, meaningful contact can reduce stigma
 - Study of Compeer program found that volunteer negative attitudes decreased, directly related to quality of bond developed
 - Research on education program with consumer testimony and dialogue revealed that contact with consumers was the key change ingredient (Pinfold et al, 2005)
 - Targeted stigma interventions

Small-Scale Intervention: Dialogues

- A form of structured contact
- Meaningful exchange of information
- Relationship builder
- Supported by Federal Consumer Affairs Office, Center for Mental Health Services, SAMHSA
- Sponsored for consumers and psychiatrists, psychologists, psychiatric nurses, social workers, and many others

Dialogues and Social Work

Students (Scheyett & Kim, 2004)

- Student attitudes towards consumers often similar to society's
- Goals were:
 - to create an experience to shift attitudes towards consumers
 - to begin partnerships between students and consumers
 - to provide experience of real relationship

University of North Carolina School of Social Work

- 10 volunteer MSW students
- 10 consumers from across the state
- Facilitator
- Full day (10am to 4pm)
- Two areas of discussion
 - understanding and partnership
 - recommendations for change

Dialogue Domains

- Understanding and partnership
 - Experiences of consumers and social work students with each other
 - Issues of identity, personhood, stigma, roles
 - What is needed for recovery, what is barrier?
- Recommendations
 - For ways to partner
 - For the social work curriculum
 - For consumer groups

Dialogue Research

- Pre and post test of students (Penn, et al, 1994)
 - social distance scale
 - perception of dangerousness scale
 - affective reaction scale
- Post interview of students
 - What did you learn?
 - What was valuable?
 - How might your practice be different?
- Transcript of dialogue analysis

Scales

- Social Distance (lower=less distance)
 - 7 questions about interactions with consumers
 - e.g. “would you rent a room to a person with MI?”
 - 0-4, 0=definitely willing, 4=definitely unwilling
- Perception of Dangerousness (higher=less dangerous)
 - 8 statements about dangerousness of consumers
 - 1=strongly agree, 7=strongly disagree
- Affective Reaction (lower=more positive)
 - 10 pairs of adjectives, rate where they fall
 - 1=most positive, 7=most negative

Results

Overall Test Scores (Pretest and Posttest)

	Pretest Mean	Posttest Mean	Mean Difference	P-value
Social Distance Scale	6.6	4.5	-2.1	p=0.0049
Dangerousness Scale	29.9	33.4	3.5	p=0.0293
Affective Response Scale	25	20.6	4.4	p=0.0256

Interview Themes

- Preconceived negative ideas about consumers

“Before the dialogue, I viewed consumers as a group with too many chronic problems and that kind of scared me.”

- Lack of understanding of reality of stigma

“This is the biggest discussion I have ever had about mental illness stigma in real life terms. It helped me to grab hold of stigma in a different way.”

Interview Themes

- Relationship and Boundaries
 - Learned about value of relationship

“What struck me the most was how much [consumers] value people listening, and how important that is...”
 - Learned about need for different type of relationship

“That’s something I had never really seen before—that your behavior can be considered cold and distant [by consumers] when you have been trained that it is ethical behavior and boundaries”

Interview Themes

- Empathy and Understanding

“I gained insight and respect for some of the frustration of...just trying to get things accomplished in the mental health system.”

- Respect for Consumer Strength

“I was struck by the ...sense of humor and the willingness to go on in the face of some pretty tough life experiences.”

Interview Themes

- Changing Their Practice:
 - Interest in Consumers

“I would be interested in working with this population now. And I would really see them now as people with complex lives and not only do they deal with their mental illness, but with all the other issues people have to deal with.”
 - Communication and Collaboration

“I will be more aware of being honest [with consumers] and trying to make it more of a partnership.”

Consumer Comments on Dialogue

- Being Valued

“I have things to say, it felt good that someone valued them.”

- Helping Others

“I hope that by sharing my story, I hope you will reach out to help someone else.”

- Value of Dialogue

“If we could keep talking we could maybe change some things”

Conclusion

- Consumer/Student Dialogues can:
 - Decrease stigma
 - Improve practice
 - Provide space for consumer voice
 - Build coalitions for ongoing change

Ideas for Action

- Augment all anti-stigma activities with social contact with consumers
 - Consumer panelists and presenters at events
 - Events with break out activities where consumers and people who do not identify as consumers can talk and work together on an activity (e.g. brainstorming ideas, community mapping resources for consumers)
- Have dialogues with key groups in the community—providers, churches, police, etc.
- Commit to having meaningful consumer involvement in every anti-stigma activity you do

References

- Couture, S. & Penn, D. (2006). The effects of prospective naturalistic contact on the stigma of mental illness. *Journal of Community Psychology*, 34(5), 635-645.
- Penn, D. L., (1994). Dispelling the stigma of schizophrenia: What information is best? *Schizophrenia Bulletin*, 20, 567-574.
- Penn, D. L., Kommana, S., Mansfield, M., & Link, B. G. (1999). Dispelling the stigma of schizophrenia: The impact of information on dangerousness. *Schizophrenia Bulletin*, 25(3), 437-466.
- Pinfold, V., Thornicroft, G., Huxley, P. (2005). Active ingredients in anti-stigma programmes in mental health. *International Review of Psychiatry*, 17(2), 123-131
- Scheyett, A., & Kim, M. (2004). Can we talk: Using structured dialogue to shift student attitudes towards consumers of mental health services. *Journal of Teaching in Social Work*, 24(1/2), 39-54.

STAMP OUT STIGMA

Train the Trainer

- **A Beginners Guide to
the
Stamp Out Stigma
Program**



Background



**From 1990 until now:
1,250 presentations to
date**

AND

- **75,000
people directly
– + ripple effect**

General

- **Funding**
- **Finding panelists**
- **Developing a curriculum and focus**
- **Flow and focus of presentation**

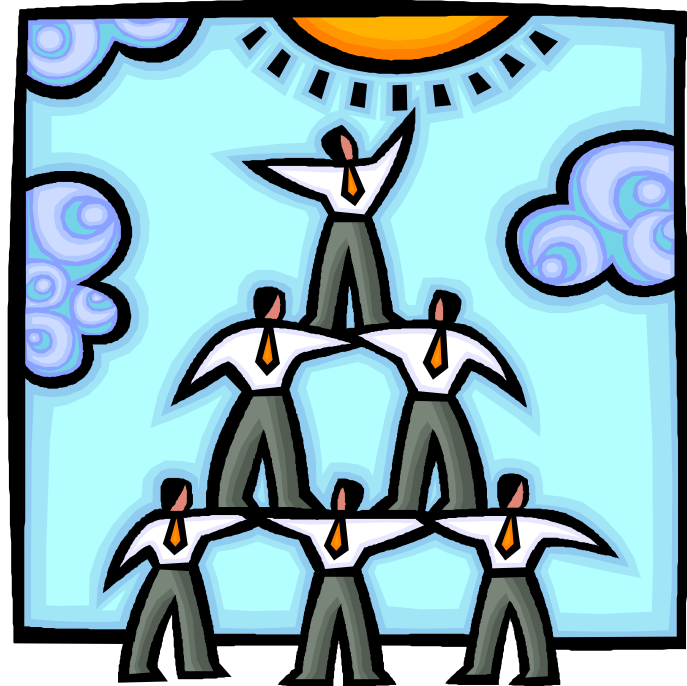


Public Speaking techniques

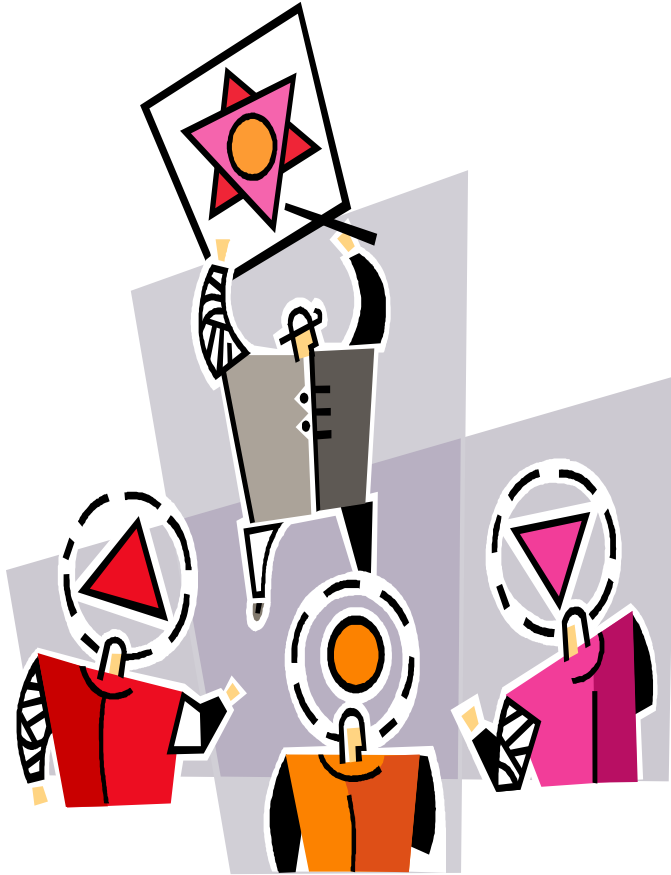
- **Practice**
- **Use video camera**
- **Room set-up**
- **Use of non-threatening questions**
- **Use of a microphone**
- **Lectern or table barrier**
- **Adapting to different venues**

Marketing the Program

- **Building a portfolio**
 - Use/develop a letterhead
 - Seek letters of commendation
 - Community building
 - Local media resources
 - Create a handout with phone number, etc.
 - Follow-up



Training Panelists

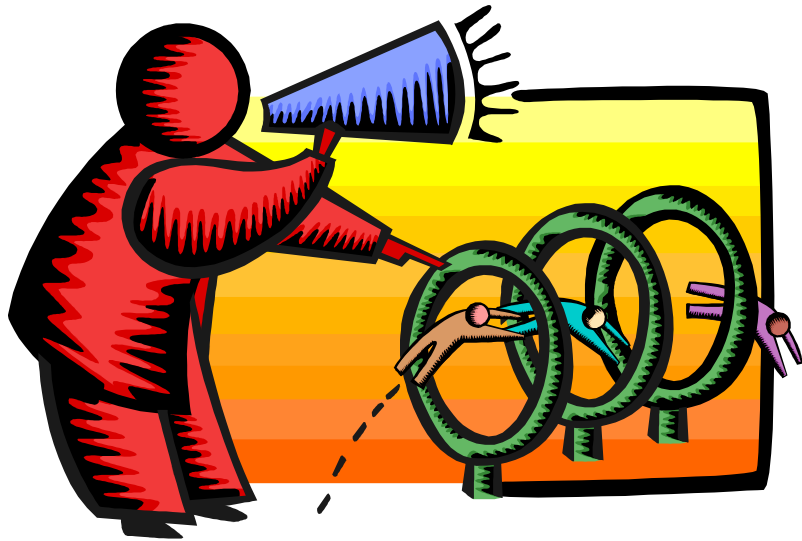


- Screening
- Locating
 - Age
 - Ethnicity
 - Diagnosis
 - Gender

Delivery

- Use of humor
- Telling the truth
- No “bashing”
- Saying only what’s comfortable
- Friendship and support
- Team effort—work as a unit

The Panel Facilitator



- The importance
- Flow and focus
- Time allotment
- Handouts
- Creating a team effort
- Balance between

Q & A

Recognizing hands

**Ensure each panelist
answers**

The Panel Facilitator (continued)



- Assisting in **GENTLY** quieting a bubbly person
- Assisting a more reserved, shy person
 - Unconstructive audience response
 - Panelist becoming symptomatic

Transportation



- The difficulty
- Finding solutions
 - County motor pools
 - Donated vehicles
 - Mileage paid
 - Asking MH organizations
 - Car pools
- Get panel where we need to be---
- On time, every time

16 Year Impact

- **Respected and sought after**
- **Changing community mindset**
 - **Courageous rather than pathetic**
 - **Not dangerous**
 - **Difference between mental illness and mental retardation**
 - **Giving audience participants opportunity to come out**



16 year Impact

- Lots of self-esteem for panelists
- Positive media coverage
- 60,000 people, plus the ripple effect
- Something positive out of negative
- Reaching law enforcement



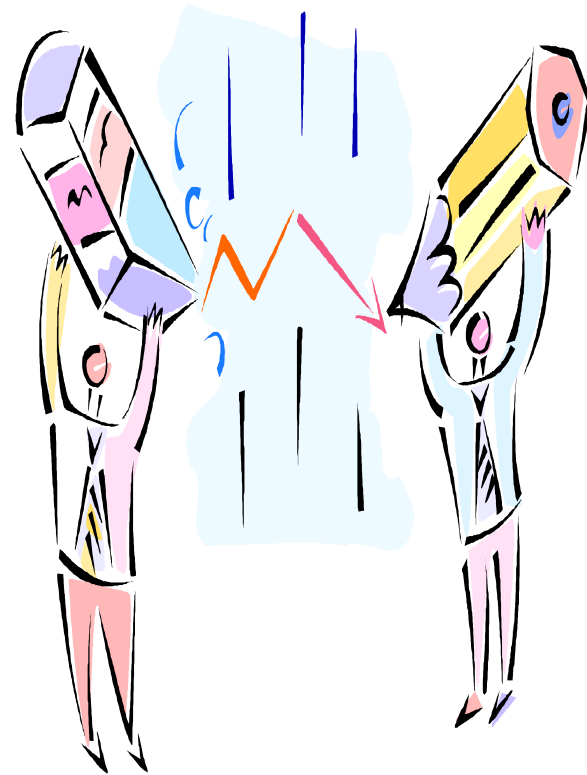
16 year Impact

- **Creating a youth SOS team**
- **BUSY Calendar**
- **Fee-for service**
- **County Contract**
- **Nonprofit status**
- **Donated van**
- **Employment opportunities**
- **Boards & commissions**



The “Nitty-Gritty” (Two people ideally)

- Record keeping
- Accounting
- Grant writing
- Grant reports
- Thank you notes
- Reconfirming every presentation
 - Getting directions
 - Parking permits, etc.



The “Nitty-Gritty”



- **Banking**
- **Executing every presentation**
 - Panelists
 - Travel arrangements
 - Expense Money
 - Substitutes
- **Correspondence**
- **Marketing**
- **Public Relations**

GOOD LUCK

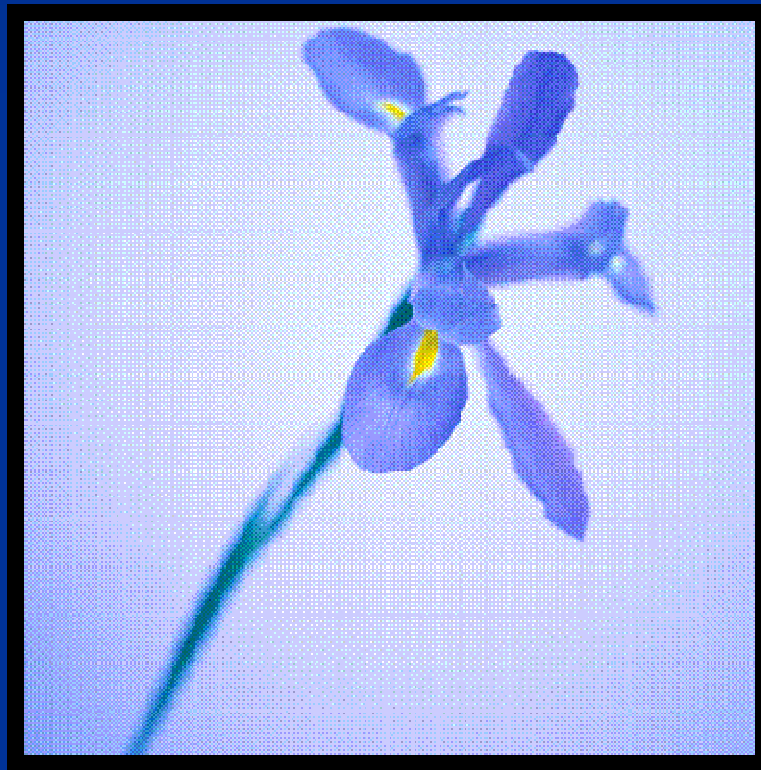


FOR INFORMATION OR **ASSISTANCE**

- **STAMP OUT STIGMA, Inc.**
1572 WINDING WAY
SUITE A
BELMONT, CA
94002
- **(650) 592-2345**
- **www.stampoutstigma.org**



The National Alliance on Mental Illness presents...

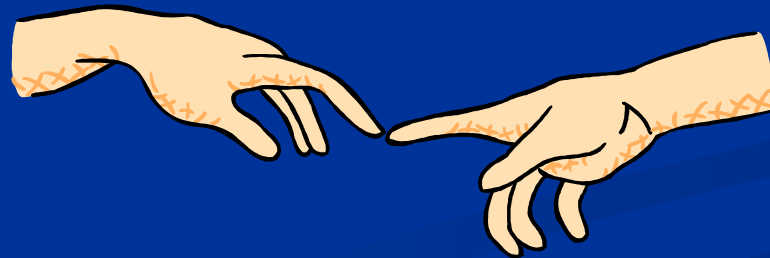


‘In Our Own Voice’

Living with Mental Illness

Recovery Education Presentation

**A contact approach
to reducing stigma**



Who are people with mental illnesses?

Our brothers, sisters, mothers, fathers, nieces,
nephews, grandparents, friends,
colleagues....even ourselves

One in five people are in
their





Meet some of our participants



The Purpose of IOOV

- To help reduce the stigma surrounding mental illnesses by putting a human face on these disorders
- To clearly define mental illnesses as brain disorders
- To expose people to a range of diagnoses including schizophrenia, bipolar, depression, anxiety, borderline, dual diagnosis, and others
- To educate the public about signs and symptoms of mental illnesses
- To discuss how treatment can lead to recovery

The History of IOOV

- Created in 1996 as “Living with Schizophrenia and Other Mental Illnesses”
- Piloted in Baltimore , MD
- Offered mainly to groups of consumers as a way to help them talk about and make sense of their experiences
- Recognized for its excellence by a growing number of audiences
- Changed to “In Our Own Voice” Living with Mental Illness in 2003
- Now in demand throughout the United States and offered to consumer groups, providers, educators, students, law enforcement, clergy, politicians, and any persons interested in learning about mental illness

Format of the 'In Our Own Voice' Recovery Education Presentation



Dark Days

Learn firsthand about the struggles of a person with a mental illness during their most difficult times.

Ask Questions:

- What do you feel like inside?
- What techniques are helpful to use when you are in crisis?
- Are dark days something that you can pull yourself out of by using willpower?

Acceptance

Learn about the process a person with a mental illness goes through to reach acceptance

Ask questions:

- Can you get someone to accept that they have a mental illness?
- Are there different levels of acceptance?
- Why is it so difficult for people to come to acceptance?

Treatment

Learn about the pitfalls and successes of treatments for those with mental illnesses.

Ask questions:

- How do you know if your medicine really works?
- How can I help my friend get treatment for her eating disorder issue?
- What do you do when doctors don't listen?

Coping Skills

Find out what skills persons in recovery use to stay well

Ask questions:

- How do you cope when you are feeling so depressed you think about doing something harmful to yourself?
- Can coping skills replace medication?
- How do you cope when friends and family don't support you?

Successes, Hopes, and Dreams

- Hear about the successes realized by each presenter
- Learn about what presenters hope and dream to be
- See recovery in a new light

Ask questions



Is ‘In Our Own Voice’
effective in reducing stigma?



Testimony from our audiences

- “It was helpful hearing people present so well and articulately on the personal and difficult experiences. It’s an excellent way to challenge misconceptions about mental illness. Thank you. It was very thought-provoking and very helpful in multiple ways”

George Washington University Student

Testimony Continued

- “This presentation personified everything that I studied in my textbooks”

University of Maryland Student

- “The presenters told it like it is”

University of Maryland Student

Research on 'In Our Own Voice'

A recent study conducted by researchers Amy Wood and Otto Wahl was published in the peer-reviewed Psychiatric Rehabilitation Journal. The study concluded that:

“NAMI's 'In Our Own Voice' Consumer Education Presentation is effective as a strategy for increasing audience knowledge about mental illness and improving attitudes toward those who experience psychiatric disorders.”

The subjects of this study were college students.

Studies show that “contact with people with mental illness yields significant improvements in attitudes about mental illness.”



Training

IOOV presenters go through intensive training in order to become speakers

During training presenters learn to....

- Create an organized and engaging presentation
- Answer tough questions
- Maintain personal boundaries
- Tailor their stories to the needs and interests of each audience- including young adults
- Facilitate discussion

Where We Are Today

- Active in 37 states
- Over 2,000 presenters trained
- Over 150,000 audience members reached

It is easy to become involved with 'In Our Own Voice' or to arrange a presentation in your area

- ✓ Visit NAMI's national website: www.nami.org to find out more



More Information

For more information, contact:

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Resources

On the Internet:

The views expressed within these resources do not necessarily represent the views, policies, and positions of the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, or the U.S. Department of Health and Human Services.

SAMHSA's National Anti-Stigma Campaign

<http://www.whatadifference.org/>

SAMHSA's Elimination of Barriers Initiative (EBI) —

<http://www.allmentalhealth.samhsa.gov>

“Developing a Stigma Reduction Toolkit”

http://download.ncadi.samhsa.gov/ken/pdf/SMA06-4176/Developing_a_Stigma_Reduction.pdf

The SAMHSA/CMHS Voice Awards —

<http://www.allmentalhealth.samhsa.gov/voiceawards/index.html>

Video highlights of the 2005 SAMHSA CMHS Voice Awards ceremony —

<http://www.stopstigma.samhsa.gov/2005VoiceAwards.htm>



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